



Queensland Advocacy Incorporated

Our mission is to promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.

Systems and Legal Advocacy for vulnerable people with Disability

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Phone: +61 2 6277 3515

Dear Committee Members

RE: Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

Queensland Advocacy Incorporated thanks the Committee for this opportunity to provide our submission (attached).

This is most welcomed as Australia is poised on the potential to engage fruitfully and with fidelity to a marginalised and often patronised section of our community.

We hope that our submission offers further insight and reinforces the perspectives of people with disability with whom we work and consult.

We look forward to the Senate's final report with keen interest.

Kind regards,

Michelle O'Flynn

DIRECTOR

Ph: (07) 3844 4200 or 1300 130 582 Fax: (07) 3844 4220 Email: qai@qai.org.au Website: www.qai.org.au

2nd Floor, South Central, 43 Peel Street, STH BRISBANE QLD 4101

QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.

Patron: His Excellency The Honorable Paul de Jersey AC

1

SUBMISSION
COMMUNITY AFFAIRS REFERENCES COMMITTEE

“The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.”

"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

Eleanor Roosevelt

About QAI – our values and beliefs

Queensland Advocacy Incorporated (QAI) is an independent community-based advocacy organisation that has for over twenty-five years campaigned for the rights of vulnerable people with disability in Queensland. With a focus on the fundamental needs of the most vulnerable people in our community, QAI has a history of avant-garde advocacy for people with disability to have supports to live an inclusive life in the community.

At QAI, we believe that all human beings are equally important, unique and of intrinsic value. Everyone should be seen and valued as a whole person, first and foremost. The human condition is such that societies tend to devalue those who do not fit within their models of perfection. These groups, including people with disability, are socially marginalised. As an organisation we seek to bring about a common vision where all human beings are equally valued.

Foreword

The archaic conception that institutional care is ‘best’ for people with disability is no longer the prevailing mindset of our society. What is becoming the exemplar is the notion and practice of social inclusiveness. In making this submission an opportunity arises in which to reflect on the progress made in the movement to community living options for people with disability living in Queensland, and how and why this has happened. There have been numerous advocacy efforts around people who have been left behind, and it is hoped that this support will provoke actions towards achieving for these people a life supported to live in a home of their own in the community.

For decades successive governments have used an excuse of “availability of resources, and appropriateness” to restrict people with disability to a second-rate existence that we would not accept for ourselves or our loved ones. The experience for many residents of institutions, hospitals, hostels, group homes and boarding houses does not compare with a life known to other citizens of Queensland.

How many people are forced to live in shared care arrangements?

“As at May 2013, there were 271 people with intellectual disability or cognitive impairment who continue to reside in long-stay health facilities in Queensland. This included 131 people with intellectual disability or cognitive impairment who were long-stay residents in public health facilities inclusive of residential health care facilities, Baillie Henderson Hospital and the Park Centre for Mental Health; a total of 12 people residing in state-funded and operated aged care facilities; and 30 people residing in various hospitals and other health services. A further 98 people with intellectual disability reside in authorised mental health service facilities in Queensland.”¹

These figures however, do not accurately capture the numbers of people residing in co-tenancies in group homes, boarding houses, hostels, or private aged care facilities. Many of

¹ Office of the Public Advocate People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation A systemic advocacy report October 2013

these people are forced into living arrangements without any consultation, any choice about where or with whom they live.

Research has shown that residents in institutions do not have their needs met. Similarly studies show that those who have been moved into community with adequate supports thrive and develop skills and personal relationships which provide freely given natural supports. It is known that when given sufficient time and resources, the benefits to the person, their family and community far outweigh any initial financial investments.

Given the wealth of learning opportunities from deinstitutionalisation in Queensland and other states, it is deeply challenging for many family members, advocates and allies that there still resides a considerable population of people with disabilities in institutions of varying sizes, locations and styles, from large hospitals, smaller clinics, boarding houses, hostels, and group homes.

Life in segregated and or congregate care breaches many of the articles of the Convention on the Rights of Persons with Disabilities. It is unlikely that life in long stay health facilities or indeed any institutions, boarding houses or hostels can comply with Articles 1, 3, 4, 5, 8, 9, 14, 15, 16, 19, 21, 24, 26, 27 or 28. (See attached addendum for details)

"No advantage is gained by remaining in an institution" (Cullen et al., 1995, p. 491) and no "... study ... (has) shown accelerated improvement over time arising from community placement" (Lowe, de Paiva, & Felce, 1993, p. 4). The results of the present study indicate that adults with intellectual disability have living conditions which are more similar to people in the community without intellectual disability and are certainly more favourable than their lives in the institution. All results report positive changes whether for adaptive behaviour, choice-making or objective life circumstances and are a reflection of the improved living environments and changed lifestyles. The nature of differential outcomes for individuals suggests that community based services may not yet be meeting all the needs of all people with intellectual disability and attention needs to be paid to individual development and especially to the quality of staff support. One could argue that the only advantage of institutions might be for bureaucratic and administrative purposes, while deinstitutionalisation and the new lifestyles of people with intellectual disability in the community are suited to addressing the needs of individuals. For the maintenance of positive lifestyle outcomes community living needs to address issues of the social environment including interrelationships between people with and without intellectual disability in the social domain. "Deinstitutionalisation and changes in Life Circumstances of Adults with Intellectual Disability in Queensland" J. L. Young 2001²

The immediate and future support needs of individuals

In order to consider the immediate support needs of individuals it is vital that they are engaged in discussions about what they want. Certainly families and supporters should be consulted, but it is long overdue that the individuals themselves are encouraged and supported to communicate in whatever means, their choices about their future. This will require considerable concerted and detailed efforts to allow residents to explore opportunities and options that they may (in some cases) never have experienced in their lifetimes.

² "Deinstitutionalisation and changes in Life Circumstances of Adults with Intellectual Disability in Queensland" J. L. Young 2001

NOT REPLACING CONGREGATE CARE FOR MORE OF THE SAME

It is important that whatever the alternative means of accommodation from congregate care, we do not merely devise a replacement model in cluster or groups.

Family members of people residing in long stay health facilities had opted for their family members with disability to remain with the status quo because of fewer choices, little information about suitable alternatives and the less desirable option of group homes.

Young (2006)³, in another comparison of two matched groups each of 30 individuals moving from Challinor to (a) small, dispersed community residences versus (b) a cluster of group residences found that both groups improved after the move from the institution; however, those who moved to the dispersed homes did significantly better.

Valuable lessons from previous closures of institutions highlight what processes work, and also indicate what measures should have been undertaken for successful outcomes for residents, their families and the communities they move to.

*"The move from the Strathmont Centre into the community has been associated with many lifestyle improvements. This has included increased family contact, more privacy, a more home-like and less institutionalised living environment, an increase in perceived life satisfaction and many improvements in residents' health. The report also highlights an 80% reduction in "behaviours of concern", which includes physical self-injury and injury to others." From the Strathmont Centre Redevelopment and Community Living Project – Summary Report, Dept. of Families and Communities, South Australian Government.*⁴

In a report from the Julia Farr Association, Purple Orange wrote *".. improvements were reported in health, family contact, privacy, personal control over money, and access to community amenities. The report also said families were generally positive, often in contrast to their anxieties at the outset, and staff also reported improvements."*⁵

However the report analysed shortcomings with the process that had not given sufficient attention or energies towards the facilitation of the development of personal relationships or engagement in ordinary community life. The lack of careful detailed personal planning was probably part of the problem, as this would have highlighted the need for a focus on building the capacity of individuals and ensuring that staff was well trained to do this work.

The issues that should be taken into account to support successful transition from institutional to community-based living.

Transition for residents in institutional settings must be prefaced with careful planning with the person at the centre of all engagements. Some people who have lived in institutions for many

³ "Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian-matched sample" Journal of Intellectual Disability Research L. Young.2006

⁴ From the Strathmont Centre Redevelopment and Community Living Project – Summary Report, Dept. of Families and Communities, South Australian Government

⁵ Purple Orange " A New Report on Familiar Issues: What the Strathmont Evaluation Could Mean for Disability Policy"

years have been burdened with undeserved reputations and acquired behaviours, which, if they exist at all, often result from a lack of exposure to societal norms. A person with limited communication means, or limited exposure to an ordinary life will need attentive supports to interpret their behaviours and means of communication if their views and wishes are to be truly captured and included in the development of options to improve their lives.

Need for Planning and Keeping the Person and The Heart of All Action

John O'Brien asked almost two decades ago: "How can we use our resources to assist the people who rely on us to live better lives?" (1989, p.5). The services people with severe disabilities rely upon for their personal assistance and daily support over a long period of time, do become life defining, suggested O'Brien. A shift in emphasis to a person-centred approach to devising supports and services will provide optimal opportunities for individuals with disabilities. This was explained in the paper "Disability Accommodation and Support Framework Report" prepared for the Victorian Department of Human Services by the Centre for Developmental Disability Studies, by Trevor R. Parmenter & Samuel R. C. Arnold.⁶

With the opportunity to plan for a future life in the community, residents of institutions must be supported with individualised, portable funding. They must also be allowed the right to choose: whether they will self-direct and self-manage their own funds; who they will engage to deliver supports and services; and most importantly where, with whom and how they live.

Perceived Cost versus Benefit

As outlined in QAI's values and beliefs all people are of equal value, equally important, and equal citizens. This is never diminished by difference of any type, and neither by perceived level of complexity of support need. All people have potential and when supported to live an ordinary life as other Australian are most likely to reach their potential. Anything less than this is a course of restriction and inhibition to that potential.

There are many would-be detractors who will argue about the costs of supporting people with complex support needs to live in the community. The research as quoted above has demonstrated that costs to governments and communities are less significant than the benefits to individuals, their families, and the communities in which people live. This is evidenced by the following:

"Spreat, Conroy, and Fullerton (2005) matched samples of 174 Oklahoma residents with developmental disabilities living in the community and in an institution to compare costs and outcomes. Community living provided significantly more hours of service, and increased opportunities for vocational and community experiences, at a significantly lower cost (US\$138,720 vs \$123,384 per person per year).

In the UK, Robertson et al. (2004) measured the quality and cost of community-based residential supports for 25 people with developmental disabilities compared with a matched group of individuals who remained in institutional care. The services were assessed twice, at 20-month intervals. Annual costs per person averaged US\$115,830 in institutional care compared with US\$96,010 in the community residences. The authors concluded that

⁶ "Disability Accommodation and Support Framework Report" prepared for the Victorian Department of Human Services by the Centre for Developmental Disability Studies, by Trevor R. Parmenter & Samuel R. C. Arnold

community residences were more cost-effective. Felce, Lowe, Beecham, and Hallam (2000) studied the cost and quality of service for adults with severe intellectual disabilities and challenging behaviours in Wales and England. They compared 17 individuals living in community houses with 17 individuals residing in institutions. The average age of the residents was 22 years, and all participants had severe behavioural problems. The authors found that community staff, though less qualified, was significantly more attentive to residents (community staff spent 22.3% of their time interacting with residents versus 7.7% in institutions). Involvement in activities increased to 35% of time per week in the community from 14.2% in institutions. Residential costs, however, were significantly higher in the community, which the authors suggest is different from studies in other countries. Over a 3-month period, community service costs averaged £22,898 per person versus £11,464 in the institution. Generally, community living seems to be more cost-effective and often less expensive than institutional care” *Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature* Raymond A. Lemay *Canadian Journal of Mental Health* 2009⁷

*“In the 2012-13 financial year, it cost the Queensland Government approximately \$76.28 million to support people with disability who are residing in health care facilities. The Public Advocate contends that at least some of these funds could be reallocated to provide people with disability living in health care facilities with more appropriate models of care and support in the community.”*⁸

Hospitalisation or most forms of congregate care bear inordinate costs that could be redirected to support an inclusive community life.

*“The way in which resources are currently applied in the disability sector also has flow-on effects to other government services. For example, people with disability under the age of 65 are inappropriately residing in hospitals due to limited community-based supports or unsuitable accommodation – ‘blocked beds’. The estimated annual cost to the health system of these blocked beds is between \$38 million and \$84 million”.*⁹

QAI contends that just as one cannot measure the value of human life, there should be no economic argument that justifies the abuse of a person’s human rights, or propagates policies or practices that denigrate or diminish the quality of life experiences for people with disability. While we do not intend to debate this issue it is important to remember that all our lives are intertwined and when a person suffers an existence that is devoid of the social norms and experiences of others, their families, friends and the community too experience loss and detraction.

In the Words of a famous Former Institutional Resident

“I rotted in St. Nicholas for 14 years, and you expect me to be a woman like any other? Do remember that I saw my friends die - over and over, time after time. In the hospital you couldn’t afford friends. Kids who tired of fighting rusted away; and if you rust young you don’t live to be old. I fought, and I survived - survived to wonder which of my enemies I had beaten and which I had just put away inside myself. I suffer jealousy whenever Rose works with

⁷ *Deinstitutionalization of People With Developmental Disabilities: A Review of the Literature* Raymond A. Lemay *Canadian Journal of Mental Health* 2009

⁸ Office of the Public Advocate *People with intellectual disability or cognitive impairment residing long-term in health care facilities: Addressing the barriers to deinstitutionalisation* A systemic advocacy report October 2013

⁹ Department of Health data (Unpublished); cited in PC. (2011). *Disability Care and Support*. Productivity Commission Inquiry Report. No. 54, 31 July 2011. p. 143.

another person with a disability. What if they take her fancy and she swaps me for them? I want to be normal, to love and be loved, crisp new love, but I still prefer not to make close bonds with mortals.

Mine is the troll's motto, "To thyself be enough." ¹⁰

The compelling stories of people with disability chronicle a history of hurt, and ignorance of our shared humanity. To continue to perpetuate this gristmill of infliction is to ignore the contribution that people with disability bring to our society, the riches of our country, the willingness of neighbourhoods to embrace diversity, and to undervalue the plethora of knowledge and skills in the sector.

The Queensland government has initiated the Joint Action Plan to transition people with disability from long stay health facilities and or nursing homes to live in the community. We are cautiously optimistic about this Plan although we share the frustration at the limited number of people who have been included in this process to date.

However, we are extremely disappointed and alarmed to learn that the Department of Communities, Child Safety and Disability Services has proposed a tender for funding of a project :- **Provision of Accessible and Sustainable Accommodation for People with Disability in Residential Aged Care or Public Health Facilities.**

Our concern is the following quote *"The target group includes people with high physical support needs, who may have additional medical support needs, living in residential aged care, or who are long stay in public health facilities.*

*In terms of accommodation design, preference will be given to either **two or three people sharing in one dwelling. This will enable the sharing of support at key times and as needed.***

One-off capital grants up to \$800,000 are available to innovative initiatives to provide accommodation for people currently living in residential aged care facilities or at risk of requiring accommodation in residential aged care or public health facilities.

The congregation of people with disabilities according to their 'support needs' offers no choice or control as intended by the advent of the National Disability Insurance Scheme. It is flagrant disregard to Article 19 of the Convention on the Rights of Persons with Disabilities to which Australia committed in 2008.

This is not a simple matter of merely accommodating people and ensuring support needs. The perpetuation of forced co-tenancy is a symptom of an archaic mindset that has not recognised its failures or the damage to human lives, families, communities or acknowledges the false economy and increased indirect costs.

A factor that has been identified as having a significant impact on the psychological well-being and behaviour of many people with an intellectual or cognitive impairment relates to the person's accommodation arrangements. This is an issue that has previously been accorded

¹⁰ "Annie's Coming Out" by Anne McDonald and Rosemary Crossley

significant attention as a consequence of reported atrocities committed in institutions in which people with mental illness or intellectual and cognitive impairments were accommodated.¹¹

A guiding principle in making accommodation arrangements is that of normalization, whereby people with intellectual disability are given socially valued roles and treated equally to those without disability, with the goal of improving their quality of life.¹² Research has shown that, even for adults with severe and profound intellectual disability, there are improvements in adaptive behaviour associated with the move from institutional accommodation to community housing.¹³

However, there remains a significant disparity between the preferences and reality of accommodation for many people with an intellectual or cognitive impairment. For many people with disability, their choice is not to be accommodated in a group home, but rather to live in an ordinary home in the community, either alone or with housemates chosen by them, in the manner that most Australians are able to choose their accommodation arrangements. Recent Australian research has recognised the desirability of taking an individualistic approach to housing for people with a disability.¹⁴

Any arrangements must recognise the importance of self-determination and autonomy and the consequent need to ensure accommodation arrangements are tailored to suit the relevant person, with appropriate tailored funding available to support independent living arrangements with services provided in the community.

An external evaluation of the delivery and outcomes of the Queensland Government's Housing and Support Program conducted in 2010 found that people with intellectual and cognitive disability or mental illness can successfully reside and participate in their community of choice, with adequate community support, stable housing and appropriate clinical case management.¹⁵

Restrictive Practices

Restrictive Practices are those practices used by funded disability service providers to respond to the behaviour of an adult with an intellectual or cognitive disability that causes harm to the adult or others. Restrictive Practices include mechanical, physical and chemical restraint, seclusion, containment and restricting access to objects.

¹¹ Refer, for example to the Basil Stafford Judicial Inquiry, which documented the ongoing abuse mistreatment and some killings of people with intellectual disability living there (1994, <http://www.cmc.qld.gov.au/data/portal/00000005/content/30013001200355733952.pdf>)

¹² Young, note 29. Young, Janet Louise, *Deinstitutionalisation and Changes in Life Circumstances of Adults with Intellectual Disability in Queensland*, Unpublished doctoral thesis, University of Queensland, 2001

¹³ *ibid*

¹⁴ Lesley Chenoweth, Natalie Clements and School of Human Services and Social Work, *Funding and service options for people with disabilities: Final Report*, Griffith University, June 2009, reporting on the 2008 meta-analysis by Parmenter and Arnold for the Victorian Department of Human Services.

¹⁵ The evaluation was conducted by the Department of Psychiatry, University of Queensland, in conjunction with the Queensland Centre for Mental Health Research (known as 'The Park').

Factors that calm and factors that escalate behaviours of concern

The use of RPs has been identified as a factor that escalates behaviours of concern. A meta-analysis of the literature regarding the use of physical restraint in child protective services in South Australia concluded that there was no robust evidence to show that physical restraint reduces either the frequency or intensity of 'challenging behaviour'.¹⁶ To the contrary, the use of RPs has been recognised to escalate behaviours of concern. Research by scholars including Carr¹⁷ and McLean and Grey¹⁸ establishes that there is a parallel reduction in behaviours of concern associated with a reduction in the use of physical restraint. Recent research by Tyrer and associates has shown not only a lack of evidence-based efficacy of chemical restraints for people with an intellectual disability, but that a placebo group, rather than a group on antipsychotics, showed the greatest positive change in behaviour.¹⁹ Webber and associates similarly note: 'overall, the evidence in favour of chemical restraint for controlling behaviours of concern such as aggression is weak'.²⁰ This is concerning, given the widespread use of chemical restraint for people with a disability over extended periods, with little or no data collected to determine treatment efficacy.²¹ They conclude:²²

Our available data to date suggest that restrictive interventions do not lead to reduction in the occurrence of behaviours of concern except in the short term (i.e. while applied) and that what is needed is a better understanding of the functions of behaviours of concern and the individual needs of the person and interventions that address those functions and needs.

The serious adverse consequences of the use of RPs for both adults and children include serious physical injury, such as asphyxia and cardiac complications and death, as well as significant adverse psychological effects on quality of life and well-being.²³

This evidence of the effects of the use of RPs is unsurprising, if we consider the likely response of any person, whether they have a disability or not, to the imposition of a Restrictive Practice, which is tantamount to abduction, imprisonment, bondage, solitary confinement, chemical sedation or sterilisation. This is exacerbated in the case of persons with increased vulnerability and diminished legal autonomy.

¹⁶ Andrew Day, Michael Daffern and Pam Simmons, 'Use of Restraint in Residential Care Settings for Children and Young People' (2010) 17(2) *Psychiatry, Psychology and Law* 230, 922.

¹⁷ Carr, EG, RH Horner, AP Turnbull, et al, *Positive behaviour support for people with developmental disabilities: A research synthesis*, American Association on Mental Retardation, Washington DC, 1999.

¹⁸ Grey, IM, RP Hastings and B McLean, 'Staff training and challenging behaviour' (2007) 20 *Journal of Applied Research in Intellectual Disabilities* 1; Grey, IM and B McLean, 'Service user outcomes of staff training in positive behaviour support using person-focused training: A control group study' (2007) 20 *Journal of Applied Research in Intellectual Disabilities* 6.

¹⁹ P Tyrer, PC Oliver-Africano, Z Ahmed et al., 'Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: A randomised controlled trial' (2008) 371 *The Lancet* 57; Lynne Webber, Frank Lambrick, Mandy Donley et al., 'Restraint and Seclusion of People on Compulsory Treatment Orders in Victoria, Australia in 2008-2009' (2010) 17(4) *Psychiatry, Psychology and Law* 562, 564.

²⁰ Webber, Lambrick, Donley et al., note 12, 564.

²¹ *Ibid* 565.

²² *Ibid* 572.

²³ The Australian Psychological Society Ltd, *Evidence-Based Guidelines to Reduce the Need for Restrictive Practices in the Disability Sector*, 2001.

Case Study 1 – Tina, a 23 year old female

Tina was being supported by a service provider who regularly sought to increase the range of Restrictive Practices they could use around Tina. As a baseline, Tina was contained for 16 hours per day and secluded for eight hours overnight. During the day she would also be placed in seclusion or have chemical restraint applied in order to control her behaviour.

Tina's behaviour arose because neither she nor her family were listened to. Tina was bored, had little meaningful activity in her life and had been isolated from the community in which she lived. The service provider showed little interest in addressing these issues when they were raised by the family. Instead, they attempted to restrict Tina's access to her family and on several occasions applied to QCAT to have the public guardian appointed, as opposed to the family member. The service provider refused to acknowledge that Tina's behaviour was a form of communication (expressing dissatisfaction) and labelled Tina as difficult and prone to 'challenging behaviours'.

Tina really wanted to move to her own place and be closer to her family. The service provider discouraged this dream. Rather, they made application to QCAT submitting that Tina could never live on her own, was unsafe to be in the community and needed high level use of Restrictive Practices. The family continued their strong advocacy for Tina and contacted QAI for assistance.

Eventually Tina was moved into her own residence, closer to her family and to a service provider who has never used any form of Restrictive Practices. Tina now has a part-time job and has become part of her local community. The 'challenging behaviours' have drastically reduced, as has the level of funding required to provide her support.

(CRPD Breaches: Articles 3, 14, 15, 16, 17, 18, 19, 20, 22, 23, 25, 26, 27, 28 and 30)

Case Study 2 – Frances, a 22 year old female

Frances was living in the community, however due to inadequate funding and inappropriate supports Frances' needs were unmet. As a result she started to display behaviours which were seen by the service provider as challenging, so much so that they withdrew from providing support. A decision was made by Disability Services to place Frances in a secure facility, contrary to the appointed guardian's requests. This meant that Frances was contained 24 hours per day, seven days a week.

Subsequent to the move all activities that Frances had previously enjoyed were ceased, as was her personal mobility and freedom. Due to boredom and an inability to move around freely, Frances began to self-harm and strike out at staff. Additional Restrictive Practices such as seclusion and chemical restraint were applied yet, unfortunately, positive strategies were not as rigorously applied. Frances began to spend large amounts of time in seclusion.

It was 18 months before activities pleasurable to Frances were re-introduced into her daily routine. This was only achieved through the strong advocacy of her family and QAI's involvement. Some 12 months later Frances remains at this facility and continues to have Restrictive Practices applied, albeit the frequency of use is decreasing.

The question to be pondered is: would any of this have occurred if appropriate funding and supports were available to Frances in the first instance?
(CRPD Breaches: Articles 3, 4, 14, 15, 17, 18, 19, 22, 23, 26, 28 and 30)

Case study 3 – Michael, a 50 year old male

Michael was living happily with his sister in a Department of Housing house. However due to a bureaucratic policy around department of housing tenancies a third person was moved in with them. This occurred without discussion or consultation with either Michael or his sister.

The co-tenant became abusive to Michael's sister. This naturally resulted in Michael becoming protective of her and beginning to hit out at the co-tenant. Eventually Michael became subject to Restrictive Practices, in particular physical restraint. Michael's 'behaviour' was not explored and he was labelled an aggressor. By placing this label on Michael, no additional support was provided to prevent the escalation, nor was any consideration given to removal of the co-tenant. Rather, there was a reliance on using Restrictive Practices to manage the situation.

Michael's advocate contacted QAI for assistance when the service provider requested ongoing approval to use Restrictive Practices. The Restrictive Practice order was revoked and additional supports were placed in the house to manage the situation. However, the co-tenant remains and the situation remains conflictual.
(CRPD Breaches: Articles 3, 4, 5, 15, 17, 19, 22, 23 and 28)

The anti-discrimination legislative framework offers theoretical safeguards against the inappropriate use of Restrictive Practices, as the use of Restrictive Practices is potentially in contravention of the statutory prohibitions against discrimination in state, federal and international law, constituting practices and treatments that would be unlawful if done to others without the disability. While it is difficult to argue that there exist grounds that justify such adverse, differential treatment, the anti-discrimination jurisdiction has not provided an effective cause of action to date in this context, primarily as a consequence of endemic problems inherent in that jurisdiction.

A report to the UN General Assembly by the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman and degrading treatment or punishment that focusses extensively on violence and abuse of persons with disability, calls for its reframing as torture and ill-treatment (specifically referring to restraint and seclusion).²⁴

French and associates note the important implications of the CRPD rights to equality and non-discrimination for the regulation of RPs and compulsory treatment, as follows:²⁵
Essentially, they will not permit treatment of persons with disability differently to other persons, except where this treatment is a positive measure designed to overcome pre-existing disadvantage, or a reasonable accommodation designed to ensure that human rights and fundamental freedoms may be exercised on an equal basis with others. For persons who

²⁴ United Nations General Assembly, *Torture and other cruel, inhuman or degrading treatment or punishment; Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/63/175, [37] – [76]; French, Chan and Carracher, note 1, 246.

²⁵ French, Chan and Carracher, note 1, 265.

have behaviours of concern, this may require substantial positive measures, such as the provision of appropriate accommodation and adequate skilled support staff to assist the person to realize their positive development potential.

QAI asserts that proactive assistance should include habilitation, education, training and enriching life experiences.

Similarly, the CRPD rights to inclusion and participation, as well as the related rights to liberty and freedom of movement, provide a lawful basis for the state to ensure persons with disability are enabled to live independently in the community with choices equal to others with the supports they require to achieve this, and to enjoy personal mobility with the greatest possible independence.²⁶

Society should be constantly examined for any systemic biases which harm vulnerable and marginalised groups, and should be challenged. This includes ensuring that everyone has adequate access to the legal system: in a civil society, all members of that society should accept responsibility for the protection and development of equality before the law. All legislation, procedures and policies that impact on people with disability with particular emphasis on those that pertain to the use of Restrictive need to be reassessed to ensure their fairness and equitable treatment of people with disability.

Forensic Detention

As a response to the Butler and Carter Reports, the ten-bed Forensic Disability Service was opened on 1 July 2011 at the Wacol precinct for the purposes of providing a forensic response for people with intellectual disability or cognitive impairment but no mental illness who are deemed to require detention in a secure facility.

The *Forensic Disability Act 2011* provides the statutory framework for the new facility. This facility is only for those people with intellectual disability or cognitive impairment subject to a forensic order (Mental Health Court - Disability) made by the Mental Health Court.

The language used in reference to people who are detained at the FDS is likely to impose a negative impression upon the general public. Nevertheless, in some instances people living under a forensic order (and particularly at the FDS) are treated very differently because they have a disability. Many of them have spent significant periods of time in detained facilities/institutions for an offence for which an 'ordinary' person may have received a fine, community access or a short term in prison. Ordinary people have the opportunity to do their time and then get out and move on with their lives. Even those who have committed the worse offences often have a right to parole and if not, know when their sentence is up and when they will be released. This is not the case for the individuals in the FDS who have no such rights granted to them and continue to spend year upon year detained.

The rhetoric is that each person would have an individualised development plan detailing the educational and training programs best suited to equip them to a return to community living.

²⁶ Article 19 and 20 of the CRPD; French, Chan and Carracher, note 1, 265.

Such planning is meant to engage the person's supporters including family, friends, neighbours and professionals involved in their lives to work to an agreed strategic approach. This would inform an individualised service response that will have a positive and informed risk taking method, have a long term focus and concentration on changes in quality of life. These service approaches (if they were implemented) would enhance competencies in community participation and presence, educate, and identify the function and triggers to offending behaviour and to reduce and redirect offending behaviour.

People within the FDS have limited opportunities to develop appropriate relationships other than with some FDS staff that may have a 'warden' demeanour that is not conducive to healthy respectful interactions. The misconception that the FDS is a prison reinforces negative and inaccurate stereotypes that can result in a cycle of inappropriate responses by staff members. This is exacerbated in circumstances where the person's only contact may be the FDS staff.

We know that in several instances family members and advocates for people detained in the FDS have been told that there is not sufficient funding to enable them to engage in planned community access activities that would enhance or develop social and practical skills. A person can only access these community activities if approval is granted. We believe that at times adversarial behaviour of some staff members can cast a pejorative impression that denies the person from accessing the very community programs that could advance their development and skills.

Our experience is that the lives of several people living in the FDS have deteriorated along with their social and practical skills.

It is interesting to note that the former Chief Practitioner once described the FDS as unfit for human habitation as its stark environment resembles the harshest prison like setting.

The intention of the FDS was for it to be a transition facility not a permanent arrangement for people with intellectual or cognitive disability who are on a forensic order. The FDS has been used as a transition point from a Health facility to Department of Disability Services while waiting for funding for support and public housing which is still not forthcoming. The only way out of being **inappropriately** detained in mental health facilities was to agree to conversion to the FDS as the beginning of transition back to community living. People however are now trapped in this institution due to lack of forward planning and commitment to necessary funding by the Department.

The FDS has not fulfilled its obligation to people with disability (whose care and lives they have been entrusted with) their families, their supporters not even to the Department. Despite the time that has passed, the large injection of money to this service, and the related experts involved in the designs of processes of the FDS its failure to support and 'habilitate' is immense.

It is deeply disturbing to us at QAI that if indeed FDS practice matched policy; funding from Disability Services and a commitment from the Department of Housing was forthcoming, it is

likely that transition for individuals who reside at FDS would be much further along with most of not all returning to community living.

In light of all of the above we have concerns that people can be lost to this system indefinitely. Since the FDS opened in 2011 no-one has transitioned out of the FDS.

The NDIS

The introduction of the National Disability Insurance Scheme has been widely optimistically received as potentially bolstering autonomous choice for persons with an intellectual or cognitive impairment in all areas of life. When coupled with the guiding principles articulated by the CRPD, the intent and purpose of the NDIS is to proactively elevate a person with disability to full citizenship in all respects. Accordingly, while the NDIS facilitates a comprehensive program for the management of services available to people with a disability, it is intended as more than a mere funding stream to enable disabled people as consumers in a marketplace. Duffy and Williams assert that the NDIS must develop and maintain the following two things:²⁷

1. A clear public account of what it means to be a citizen. It is only if we know what we mean by, and expect from, citizens that we can have any sensible conversation or research process to determine whether the NDIS is successful in its first goal: ensuring people get what they need to advance their life chances in support of citizenship.
2. Work hand in hand with people living with disability and their families to make sure the process feels respectful, effective and enabling at every stage. The NDIS process must be co-designed with people living with disability; but even more importantly for the future it must be accountable to them.

When the approach is changed, by empowerment, enablement and ensuring a person with a disability is scaffolded by support from the right relationships, the perspective on that person can change from a negative to a positive one and their status can be elevated to equal citizenship. When perceptions and expectations are changed, our approaches, behaviours and responses also implicitly change. When we remove the burdens we place upon people, they can flourish and respond accordingly.

When an approach of respect, autonomy and enablement is integrated with practical supports and safeguards, relationships are correctly balanced. We return control and respect to formerly marginalised people and reduce or remove the use of Restrictive Practices.

It is important that support for vulnerable people with disability (including those purported to communicate at times in unique and possibly challenging ways) is viewed in the same context as the interdependency of societal norms.

Block Funded Arrangements

As governments seek an economical approach to welfare reform individualised funding became more and more unavailable to people with disability with the state preferring to hand

²⁷ Simon Duffy and Robbi Williams, *The Road to NDIS: Lessons from England about Assessment and Planning* (JFA Purple Orange, 2012).

large sums of money to service providers and to provide supports to a determined number of people. When economic pressures are brought to bear on the state, savings are sought and often at the expense of the most vulnerable people in our communities. Block funded arrangements are made with non-government service providers and not with the people who are meant to be 'served', and denies people the freedoms that others can enjoy without conscious thought. It is untenable for many people to remain in this restrictive arrangement.

"At the philosophical level, opponents of widespread tax cuts often make arguments that are a variant of the oft-quoted view of former US Supreme Court Justice Oliver Wendell Holmes that "taxes are what we pay for civilized society", although this leaves open the questions of how we define civilized society and how much of civilized society we actually want to buy."²⁸

This approach prompted a proliferation of group homes and "forced co-tenancies" and despite all the research and legislative reform regarding restrictive practices there is no data regarding the number of people who were imposed a restrictive practice order once they were made to share care.

A popular ground swell of support around the Young Care model of shared care ensured the establishment of more congregate care arrangements. This has not addressed the needs of those people who aspired to move out of aged care – they were merely placed into settings of 'younger care'.

Congregate care results in a sharing of supports and therefore minimises or over-rides individual choices and freedoms from when to get out of bed, what activities to undertake, when and with whom to share these activities and limits opportunities for ordinary life. Life is reduced to a series of 8 hour shifts, and individuals must accommodate the ease and expediency of the service provider. This severely constrains opportunities to explore more diverse experiences, enjoy personal freedoms or develop relationships with other members of society.

Any complaints about co-tenants or support workers may be repressed or unreported due to fear of eviction especially when the service provider is also the landlord. Despite widespread understanding and acknowledgement of the dire conflicts of interest that this type of arrangement presents, it is still a very common practice.

There is a somewhat unhealthy departmental collaboration between the Department of Housing and Disability Services Queensland in that eligibility to public and social housing is contingent on the adequacy of the funding support package. This would be discriminatory process as any other eligible public housing clients is not scrutinised in this fashion. While we understand their concern about ensuring the person is adequately supported, it does not allow for informal and unpaid supports for be recognised.

The NDIS has prompted state governments to move towards unblocking funding. It is a small start in the right direction. However, the individualisation of funds will not inject sufficient supports for the majority of people who have been forced into these circumstances in the first

²⁸ "CANADA'S QUIET BARGAIN The benefits of public spending" By Hugh Mackenzie and Richard Shillington

instance. Waiting for the complete roll-out of the NDIS is an abdication of state government responsibility to these vulnerable people who may be unable to find another place to live or have enough funds to meet their support needs.

Furthermore neither the NDIS to date, nor the state departments of housing and Disability Services have addressed the housing needs for people to move from congregate care to a home of their own, where, how and with whom they wish to live.

Cost of living to residents

Whether a person with disability resides in a group home (often with the service provider as lessee or landlord), an aged care facility, any large residential; hospital; mental health facility; or forensic disability facility, the fees charged for accommodation and 'board' or food is a minimum of 85% of their Disability Support Pension. We are aware that some places take all of the person's DSP and dispenses an 'allowance' – sometimes as little as \$5 per week. Hostels and boarding houses regularly dispense medication to residents with little oversight or monitoring of this practice.

We are very alarmed at the prospect that the Federal Minister for Department of Social Services may cease payment of DSP to people in psychiatric confinement. (See page 193 of the Mid-Year Economic and Fiscal Outlook ²⁹--

The Government will achieve savings of \$29.5 million over four years from 2014-15 by ceasing payment of social security benefits to people who are incarcerated or confined in a psychiatric institution under state or territory law due to serious criminal charges because they were considered unfit to stand trial or were not convicted due to mental impairment. This will ensure the same social security treatment of people in the criminal justice system whether they reside in a psychiatric or penal institution.

The non-economic rationale for the change is the achievement of parity in social security treatment across the criminal justice system. Psychiatric detention is not part of the criminal justice system.³⁰ This proposal is based in a factual misunderstanding with regard to the nature of criminal responsibility. Psychiatric detention is not a part of the criminal justice process; it is part of a parallel forensic process that involves no finding of criminal responsibility and no conviction.

People placed in psychiatric detention still have financial responsibilities such as rent, the welfare of those dependent upon them, education and necessities. For some people residing in such facilities a part of their treatment or habilitation includes 'limited community treatment' (i.e. attending TAFE courses, shopping, etc.) which requires the person to have funds to pay for these activities. Many people pay for some of their activities and supports to

²⁹ Mid-Year Economic and Fiscal Outlook 2014-15 DECEMBER 2014 Statement by The Honourable J. B. Hockey MP Treasurer of the Commonwealth of Australia and Senator the Honourable Mathias Cormann Minister for Finance of the Commonwealth of Australia For the information of honourable members

³⁰ Except where a prisoner develops a mental illness after their incarceration and is moved into psychiatric detention.

attend them as the state services are already under-funded.. Depriving people of income promotes institutionalisation, creating dependency and learned helplessness.

While it may appear that this information is not relevant to this inquiry, for some people with complex support needs, life has been reduced to indefinite detention in settings such as mental health facilities and or forensic disability facilities.

Service and funding models

QAI is genuinely pleased that the impending NDIS has forced the state of Queensland to finally begin to address the crushing and debilitating practices that have been inflicted upon people with disabilities for decades. However, it is clear that no matter which political party holds government, the relevant ministers are usually briefed by the same bureaucrats who have held close to their own outdated personal views.

There is a tendency for politicians to hear only the voices of those with the most resources, the larger presence and therefore do not always hear from individual people with disability who have a wealth of experiences from appalling living conditions to overcoming abuse and neglect to living a life directing their own supports and services. The loud voice of service providers (funded by the same department) dominates the voices of the very people about whom this inquiry is focussed.

Of course the word "choice" is a key and now popular catchphrase used by the same service sector that unconsciously at times does everything to eliminate the autonomy that choice should lead to. Family members too can sometimes supersede the wants and wishes of the person with disability as they too have competing interests.

Advocacy that is independent of these conflicts is important to ensure that the person is not left to make choices from rotten apples. It is not appropriate to ask a person who has always lived in a nursing home, or a group home if they would like to stay, or if they would like to share with another of their 'co-tenants'. Rather it is important that in the pre-planning stages people are encouraged to create a vision for how they would like to live. This may require that people are supported to meet other people with disabilities who are living in the community with adequate supports in a variety of living arrangements that are consistent with ordinary community expectations and situations.

As Queensland moves towards the implementation of the NDIS an upsurge of new service providers are emerging and we are concerned that some of these are being established by people with little understanding of the CRPD, or engage with the civil society about 'right relationships' between the person with a disability as an empowered employer and a service provider as an employee. New services are still offering 'programs' that would seem to own a person from cradle to grave – education for children, day services, employment services, accommodation services, respites services, and even legal services such as guardianship matters, wills and trusts.

This kind of ownership of a person is steeped in traditional and archaic service models that have been the propagation of abuse and cover-up.

There has however, been some innovative service models created out of almost nothing in the past, and they are still flourishing despite the cessation of opportunity to replicate this on many geographic locations.

It is the small neighbourhood responsive individualised service provider that has time and again, proven to be most flexible, most creative and most person-centred in their approach to delivering what their clients have requested. It is therefore vital that government reverse its traditional thinking and pay keen attention to the small voices in the sector, rather than the larger organisations that will find it more difficult to make radical changes to their methods.

Now more than ever the voice of people with disability and their families should be heard first and foremost, and changes in what information is sought and how it is gleaned for quality assurance, should be of utmost importance.

In the words of Eva Cox: *"In a civil society, we need to recognise the supreme importance of social connections which include plenty of robust goodwill to sustain difference and debate... I want to persuade those in high places to recognise that we are social beings."*³¹

³¹ 5 Eva Cox, *Broadening the Views*, The 1995 Boyer Lectures: A Truly Civil Society.

ADDENDUM TO QAI'S SUBMISSION

“The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.”

INDICATORS TO THE

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

CRPD Articles that long stay health facilities and institutions fail to comply with or against which they make regular breaches.

Article 1 Purpose “...the inherent dignity of persons with disability is promoted and respected.”

Article 3 General Principles “...Full and effective participation and inclusion in society, the freedom to make one’s own choices, independence and full and effective participation and inclusion in society”

Article 4 General Obligations

- All human rights and fundamental freedoms of persons with disability are promoted, protected and fulfilled by laws, policies and programmes.
- All laws, regulations, customs and practices that constitute discrimination on the ground of disability have been modified or abolished.
- All policies and programmes take into account the promotion and protection of the human rights and fundamental freedoms of persons with disability.
- All action and practices of public authorities and institutions is consistent with the human rights and fundamental freedoms of persons with disability.
- There is no discrimination on the ground of disability by any person, organisation or private enterprise.
- Professionals and staff working with persons with disability are trained to recognise and facilitate the realisation of the human rights and fundamental freedoms of persons with disability.
- The full realisation of economic, social and cultural rights is pursued to the maximum extent of available resources.
- The full realisation of economic, social and cultural rights is pursued within a framework of international cooperation, where necessary.
- The civil and political rights of persons with disability are immediately realised.
- Representative organisations for children and adults with disability are closely consulted and actively involved in the development and implementation of legislation and policies to

implement the CRPD and all other decision-making processes concerning issues relating to persons with disability.

- Existing provisions, which are more favourable than those provided the CRPD, are preserved.

Article 5 Equality and non- discrimination

- The law is the same for persons with disability as it is for others.
- The law is applied to persons with disability in the same way as it is applied to others.
- The law shields persons with disability from harm in the same way it does for others.
- Persons with disability are able to use the law to protect or pursue their interests on an equal basis with others.
- All appropriate steps are taken to ensure the provision of reasonable accommodation of the needs of persons with disability.

Article 8 Awareness Raising

- The community is receptive to the human rights of persons with disability.
- The community has positive perceptions of persons with disability.
- Stereotypes, prejudices and harmful practices relating to persons with disability are effectively combated at all levels of society and in all areas of life.
- The capability and contribution of persons with disability is effectively promoted at all levels of society and in all areas of life.
- The media portrays persons with disability in a manner that is consistent with their human rights and dignity.”

Article 9 Accessibility “...Persons with disability have access to new information and communications technologies and systems, including the Internet.

- Information and communication technologies and systems are from the outset designed, developed, produced, and distributed so as to incorporate accessibility features.
- Information and communication technologies and systems may be made accessible to persons with disability at minimum cost.”

This measure is very unlikely to be addressed by the autocratic regime of any form of congregate care.

Article 14 Liberty and security of the Person

- Persons with disability enjoy personal freedom on an equal basis with others.

- Persons with disability are free from interference with their person on an equal basis with others.
- Persons with disability are not deprived of liberty without lawful and proper reason.
- The existence of impairment or disability (of itself) is never a reason for deprivation of liberty.

It is acknowledged that from time to time some people with disability may be deprived of their liberty. However, for many people their lack of choice or say about where, with whom or how they live has meant a life where their freedom and liberty is removed particularly in the areas of forced co-tenancy, institutional or group living and shared care arrangements.

Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

- Persons with disability are effectively protected from torture, and from cruel, inhuman, and degrading treatment or punishment.
- Persons with disability are not subject to medical or scientific experimentation without their consent.
- Persons with disability who do not have the capacity to consent are subject to special protection from medical and scientific experimentation.
- All effective measures are taken to protect persons with disability from torture, and from cruel, inhuman and degrading treatment or punishment.

Despite assurances to the contrary, anecdotal reports suggest it is likely that breaches are common everyday practices.

Article 16 Freedom from exploitation, violence and abuse

- Persons with disability are effectively protected from all forms of exploitation, violence and abuse.
- Protection from exploitation, violence and abuse is effective both within and outside the home (that is, both in the public and private spheres).
- Women and girls with disability are effectively protected from all forms of exploitation, violence and abuse that have a gender dimension.
- Children and young persons with disability and older persons with disability are effectively protected from all forms of exploitation, violence and abuse that have an age dimension.
- Persons with disability, their families and carers are effectively informed and educated in relation to strategies to avoid, detect and report all forms of exploitation, violence and abuse.
- There are effective laws and policies that ensure that harms against persons with disability are identified, investigated and prosecuted.

- Laws, policies, programmes, protective and other services that relate to the prevention, detection, investigation and prosecution of harms against children and adults with disability are age, gender and disability sensitive

- All specialist facilities and programmes for persons with disability are effectively monitored by independent authorities to safeguard against exploitation, violence and abuse of persons with disability.

Despite the CJC Inquiry into Basil Stafford Centre and the recommendations for closure, that facility is still being utilised to house and contain people with disabilities. Advocacy organisations report that to some extent some of those residents who remained did so to avoid being moved to another form of congregate care in a group home

Institutional life is secretive with the hope that those charged with the care and protection of residents will do so with vigilance and integrity. It is hidden from the eyes of the public - the very eyes of those who might report anything untoward.

Yet when people with disabilities and or their families and supporters have made complaints against service providers, hospital staff, workers, it is often dealt with by the government department who has an unenviable reliance on the same respondent and is therefore not without conflict of interest and not the least independent.

It is reported that the use of Restrictive Practices, appear to be common occurrences in every type of congregate care which is clearly in breach of articles 14, 15 and 16.

Article 19 Living independently and being included in the community

- Persons with disability live in the community with choices equal to others.
- Persons with disability are included, and participate, in the community.
- Persons with disability are able to choose their place of residence on an equal basis with others.
- Persons with disability are not obliged to live in any particular living arrangement.
- Persons with disability have access to a range of in-home, residential and other community support services necessary to support living and inclusion in the community and to prevent isolation and segregation from the community.
- Community services and facilities for the general population are available to persons with disability on an equal basis with others and are responsive to their needs.

Breaches of Article 19 are undoubtedly the crux of any objection and opposition to the notion of congregate care and institutional life. As mentioned early in this paper the autocratic dictums of how and where a person lives is a paternalistic imposition that no other Australian citizen would be forced to bear. The archaic courses from our past belong exactly there - in our history. The lives of people with disabilities who are residents (of any forms of institutional life no matter how large or small) may be owed a huge debt by government and community for support and restitution to a decent life in community.

Article 21 Freedom of expression and opinion, and access to information

- Persons with disability enjoy freedom of expression on an equal basis with others
- Persons with disability enjoy freedom of opinion on an equal basis with others.
- Persons with disability have freedom to seek, receive and impart information and ideas on an equal basis with others.
- Persons with disability are able to seek, receive and impart information and ideas through all forms of communication of their choice.

It is uncertain that people with disability living in long stay health facilities or other form of institutional life will enjoy such freedoms of expression without some form of retribution if they express dissatisfaction with their lack of liberty, freedoms and choices. Therefore it is unlikely that some such facilities would reasonably and responsibly provide access to information about representation for complaints processes, or other options available

Article 24 Education

- Education of persons with disability is inclusive at all levels of the education system.
- Persons with disability have access to life-long learning, including general tertiary education, vocational training and adult education.
- Education is directed to:
 - The full development of human potential and sense of dignity and self-worth;
 - Strengthening of respect for human rights, fundamental freedoms, and human diversity;
 - The development of personality, talents and creativity, and mental and physical abilities, to their fullest potential;
 - Enabling persons with disability to participate effectively in a free society.
- Persons with disability can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.

For people with disability who reside in long stay health facilities and other institutions, life rarely resembles the same routines, freedoms and opportunities afforded to other citizens. This includes access to an education that provides learning and development of the person, their skills and personal knowledge pursuits.

Article 26 Habilitation and rehabilitation

Persons with disability have access to habilitation and rehabilitation services that will allow them to attain and maintain:

- Maximum independence;

- Full physical, mental, social and vocational ability;
- Full inclusion and participation in all aspects of life.
- Habilitation and rehabilitation services begin at the earliest possible stage.
- Habilitation and rehabilitation services are based on the multidisciplinary assessment of the person's individual needs and strengths.
- Habilitation and rehabilitation services support persons with disability to participate and be included in the community, and in all aspects of society.
- Habilitation and rehabilitation services are available to persons with disability in local communities, including in rural areas.
- The participation of persons with disability in habilitation and rehabilitation services is voluntary.
- Habilitation and rehabilitation professionals and staff receive comprehensive initial and continuing education.
- Persons with disability are informed about, and have ready access to, assistive devices and technologies to assist them with habilitation and rehabilitation.

If facilities actually met the indicators of Article 26, then stays in any institution would be temporary and short lived – therefore adopting a least restrictive approach. However as outlined in this submission, habilitation and rehabilitation is threatened by the proposed revocation of access to Disability Support Pension and exacerbated by services and systems that are already underfunded and do not deliver on their proposed programmes.

Article 27 Work and employment

- Persons with disability have access to work on an equal basis with others.
- Persons with disability have the opportunity to gain a living in a freely chosen or accepted labour market and work environment.
- Persons with disability have access to open, inclusive and accessible employment.
- Persons with disability have access to reasonable accommodation of their impairment and disability related needs in the workplace.
- Persons with disability have access to work experience in the open labour market.
- Vocational and professional rehabilitation, job-retention and return-to-work programmes for persons with disability are promoted.

Anecdotal evidence suggest with the exception of some residents in group homes, employment is rarely a typical experience for people with disability living in long stay health facilities or other forms of institutions, and open employment with award wages even less likely.

Article 28 Adequate standard of living and social protection

- Persons with disability have access to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, without discrimination on the ground of disability.
- Persons with disability enjoy continuous improvement of living conditions without discrimination on the ground of disability.
- Persons with disability have access to appropriate and affordable services, devices and other assistance for disability-related needs.
- Persons with disability have access to public housing programmes.

For many residents of shared care facilities, access to their personal funds is denied, as they often have a Financial Administrator appointed who makes all decisions about their finances. This can mean the person may not know how much money they have, and it is deemed that they do not need any money for personal expenses if all matters in their lives are controlled by the facility and its staff.

Institutional life is often barren of choice in simple matters of diet, exercise, clothing and social opportunities.

Most importantly if a person is deemed to have their fundamental needs of shelter, food and clothing met by a facility, their access to public housing is often denied, reinforcing their dependence upon a facility that they may well wish to leave. This effectively imprisons a person indefinitely.